Family Caregiving During the COVID-19 Pandemic

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ABSTRACT

Background and Objectives: The coronavirus disease 2019 (COVID-19) pandemic has negatively impacted persons with existing chronic health conditions. The pandemic also has the potential to exacerbate stresses of family caregiving. We compare family caregivers with non-caregivers on physical, psychosocial, and financial well-being outcomes during the pandemic and determine family caregivers most at risk for adverse outcomes.

Research Design and Methods: We conducted a cross-sectional online survey of 576 family caregivers and 2,933 non-caregivers from April-May 2020 in Pittsburgh, PA region with a national supplement. Outcome measures included concurrent anxiety, depression, fatigue, sleep disturbance, social participation; and financial well-being); and perceived changes due to COVID-19 (loneliness, financial well-being, food security). We also measured socio-demographic; caregiving contextual variables; and COVID-related caregiver stressors (COVID Caregiver Risk Index).

Results: Controlling for socio-demographics, family caregivers reported higher anxiety; depression; fatigue; sleep disturbance; lower social participation; lower financial well-being; increased food insecurity (all p < .01) and increased financial worries (p=.01). Caregivers who reported more COVID-related caregiver stressors and disruptions reported more adverse outcomes (all p < .01). In addition, caregivers who were female, younger, lower income, providing both personal / medical care, and providing care for cognitive / behavioral / emotional problems reported more adverse outcomes.

Discussion and Implications: Challenges of caregiving are exacerbated by the COVID-19 pandemic. Family caregivers reported increased duties, burdens, and resulting adverse health,

psychosocial, and financial outcomes. Results were generally consistent with caregiver stress-health process models. Family caregivers should receive increased support during this serious public health crisis.

BACKGROUND AND OBJECTIVES

The coronavirus disease 2019 (COVID-19) pandemic has caused widespread negative impacts on individuals' employment, financial well-being, social relationships, and physical and mental health. The pandemic has been particularly devastating for vulnerable populations, and there is evidence that existing health disparities are being exacerbated as a result (Dorn, Cooney, & Sabin, 2020). In particular, adults with chronic health conditions, and individuals with physical and cognitive impairments are more vulnerable to the health effects of COVID-19. These individuals are also more likely to rely on family caregivers to maintain their health and well-being. However, the COVID-19 pandemic and subsequent social distancing requirements may have also made it more difficult for caregivers to provide essential care to family members with disabilities.

Family caregivers are estimated to represent 21.3% (53 million) of the U.S. adult population (AARP and NAC, 2020). Under normal circumstances, caregiving can be complex and potentially stressful, involving help with daily household, self-care, and mobility tasks; provision of emotional and social support; help with health care and medical tasks; health care coordination, decision making and advocacy; and surrogacy (Schulz & Eden, 2016). While offering some benefits (e.g., satisfaction from taking care of a family member or friend; increased confidence; meaning and purpose) (Brown & Brown, 2014; Roth, Fredman, & Haley, 2015), caregiving can also compromise the health and well-being of caregivers (Schulz, Beach, Czaja, Martire, & Monin, 2020). The COVID-19 pandemic has the potential to exacerbate the potential stresses of family caregiving. The goal of this paper is to present empirical evidence on the impacts of COVID-19 on family caregiver stress, health, and well-being; and to determine

sub-groups of caregivers who are at highest risk for negative pandemic impacts in order to target potential policy and interventions.

Adaptations of classic stress-health process models have been proposed to explain impacts of family caregiving on caregiver health and well-being (Pearlin, Mullan, Semple, & Skaff, 1990; Schulz & Martire, 2004). In these models, the caregiving-related stressors, and the inability to adequately cope with them, are assumed to contribute to negative emotional, physiological, and behavioral responses that compromise well-being and put the caregiver at risk for physical and psychiatric disease. While COVID-19 has had broad negative effects on the lives of virtually everyone, it may uniquely affect caregivers by limiting access to health care and support services for themselves and the care recipient; by raising concerns about the increased vulnerability to and heightened adverse impact of COVID-19 due to existing chronic disease and frailty; and by exacerbating existing conditions such as social isolation, financial hardship, anxiety and depression, fatigue, and poor sleep. More specifically, the COVID-19 pandemic involves a variety of factors that may directly impact: (1) *primary stressors* through worsening care recipient physical and mental health, increased caregiving demands, and reduced ability to access formal healthcare for the care recipient; (2) *secondary stressors* like increased financial difficulties and family conflict; and (3) *stress appraisals* of increased physical, emotional, and financial difficulties of providing care. These negative impacts on stressors and appraisals may translate into adverse effects on physical, emotional, social, and economic caregiver well-being.

The impact of COVID-19 on family caregivers has received attention from a wide range of advocacy groups (e.g., National Alliance for Caregiving, AARP, Alzheimer's Association, Family Caregiver Alliance, American Cancer Society), but empirical data on how the pandemic

has affected family caregivers is sparse. Two recent reports highlight the psychological effects of COVID-19 on the general population, including increased prevalence of depression and serious psychological distress (Ettman et al., 2020; McGinty, Presskreischer, Anderson, Han, & Barry, 2020). A higher risk for depression was associated with lower income and savings and more COVID-related stressors (e.g., job loss, financial problems, death of someone close due to COVID) (Ettman et al., 2020); younger (age 18-29) and lower income adults reported the highest levels of psychological distress (McGinty, Presskreischer, Han, & Barry, 2020).

Existing data on the impact of the COVID-19 pandemic on caregivers, are somewhat limited (Frangiosa, Biggar, Comer, & Roniger, 2020; Park, 2020). Park (2020) reported that long-term caregivers (> one year; n = 662) reported more negative somatic physical symptoms (headaches, body aches, abdominal discomfort) than either short-term caregivers (n = 689) or non-caregivers (n = 3,433) during the pandemic. Caregivers, both short- and long-term, also reported worse mental health and greater fatigue than non-caregivers. In another series of web-based surveys of dementia caregivers conducted March-June 2020, current dementia caregivers reported higher levels of stress-related symptoms (e.g., sleep problems, difficulty concentrating, hyper-vigilance), reduced ability to care for their care recipient, and reduced access to support groups (Frangiosa et al., 2020).

This paper aims to address the lack of comprehensive empirical data on the impact of the COVID-19 pandemic on family caregivers. Prior work has focused on limited outcomes and caregiving sub-populations, has not included COVID-related caregiving-specific stressors, and / or has not included important caregiving contextual variables (e.g., caregiver-care recipient relationship, co-residence, care recipient condition(s) requiring care, specific caregiving tasks performed). We report data from a large web-based survey of family caregivers and a

comparison non-caregiver sample conducted in April / May 2020. We focus on a range of physical, psychological, social, and financial well-being indicators, both concurrent (i.e., during pandemic), and perceptions of changes due to the pandemic. To assess impacts on primary and secondary stressors and appraisals, we also focus on COVID-related effects on caregiving activities, burdens, access to healthcare, and care recipient physical and mental health. A major focus of the paper is to examine factors that place family caregivers at highest risk for negative impacts of COVID-19. The paper addresses two over-arching research questions:

1. How do current family caregivers compare to non-caregivers on physical, psychological, social, and financial well-being during the pandemic and on perceptions of changes due to the pandemic? Importantly, what is the differential impact of the pandemic on caregivers and non-caregivers?

2. Among family caregivers, who is most at risk for adverse physical, psychological, social, and financial effects?

RESEARCH DESIGN AND METHODS

Sampling and Participants

An online survey was conducted between April 15 and May 8 with the University of Pittsburgh's University Center for Social & Urban Research (UCSUR) research registry panel members of Pittsburgh region residents. Surveys and other studies used to recruit registry members employed a combination of probability and nonprobability sampling designs. The research registry has been constructed over the past ten years by recruitment through probability survey and other population-based clinical studies conducted by UCSUR. Registry members represent a broad range of sociodemographic characteristics, including age, income, education, and employment status, and are broadly representative of the Pittsburgh region. Studies of family

caregivers recruited using the registry have appeared in the peer-reviewed gerontology literature (Beach, Kinnee, & Schulz, 2019; Xu, Liu, & Beach, 2020). Emails were sent to 7,989 registry members (with three follow-ups of non-respondents), resulting in 3,225 responses for a 40% response rate.

The following question was used to screen for current family caregivers:

"Are you currently providing unpaid care to a spouse, parent, child, other relative, partner, or friend to help them take care of themselves because of a chronic illness or disability? This may have included helping with personal needs, household chores, or medical / nursing tasks. It might also be managing a person's finances or arranging for outside services. This person does not need to live with you." [y/n] Responses were obtained from 489 current family caregivers and 2,736 non-caregivers.

In order to broaden the geographic reach of the survey, we provided a link to the survey to various local and national disability and caregiver organizations for distribution to their members. This link was open April 22-May 27, 2020, and resulted in 327 additional completed surveys, including 130 family caregivers and 197 non-caregivers. In summary, the final sample for this analysis included 619 family caregivers and 2,933 non-caregivers. This paper focuses on 576 family caregivers of community residing recipients, eliminating 43 caregivers of persons residing in assisted living or long-term nursing facilities (UCSUR and NRRTC, 2020). The study was approved by the University of Pittsburgh Human Research Protection Office.

Measures

Four main categories of measures are summarized: (1) socio-demographic variables; (2) caregiving context variables; (3) COVID-specific risk variables; and (4) physical, psychological, social, and financial outcomes.

Socio-demographic variables. We collected standard socio-demographic information from both family caregivers and non-caregivers. These included sex and age (both caregiver and care recipient), and caregiver race, education, household income, household size, marital status, and employment situation. See Tables 1 and 2 for variable coding.

Caregiving context variables. These included whether the care recipient lived with the caregiver, the care recipient disability or condition(s) that required help, the relationship between the caregiver and care recipient, and the specific type(s) of care provided to the care recipient. See Table 2 for variable coding.

COVID Caregiver Risk Index (CCRI). Caregivers were asked "*We are interested in how the COVID-19 (coronavirus) crisis has affected people who are providing unpaid care to loved ones in the community. Has the coronavirus crisis had any of the following impacts on you and your care recipient*? A list of 12 potential impacts of COVID on caregiving duties, burdens, and care recipient health were presented (see Table 2), and respondents could endorse / check any that they judged relevant to their situation. An exploratory factor analysis of the responses (coded absent = 0 / present = 1) revealed that all items loaded on a single factor (eigenvalue = 3.20). We created the *COVID Caregiver Risk Index (CCRI)* by summing the simple number of items endorsed (range 0 -12). This is a summary measure of the effects of the COVID-19 pandemic on caregiver primary and secondary stressors and stress appraisals.

Outcome variables. We examined six <u>concurrent</u> (during pandemic) outcomes and three <u>perceived changes due to COVID-19</u> outcomes for both family caregivers and non-caregivers. To assess concurrent outcomes, we used the well-validated *Patient-Reported Outcomes Measurement Information System (PROMIS)-29 Profile v2.0* 4-item short forms for anxiety, depression, fatigue, sleep disturbance, and ability to participate in social roles and activities in the past seven days. The *PROMIS-29* short forms are universal, allowing for comparisons across multiple populations, and are converted to T-scores with a mean of 50 (SD = 10) for the adult general population. All short forms had high reliability (α = .87 - .95) in the current sample. Concurrent financial well-being was measured with an adapted version of the 11-item *Comprehensive Score for Financial Toxicity (COST)* scale (de Souza et al., 2017). For two of the items that refer to "my illness," or "my cancer," we substituted "the COVID-19 pandemic." Higher scores on the scale mean higher financial well-being, and Cronbach's α = .87 in this sample.

The three items measuring <u>perceived change due to COVID-19</u> were developed specifically for this survey or drawn from existing national COVID-related surveys. Change in loneliness was measured by asking "*Compared to before the start of the coronavirus outbreak, would you say that feelings of social isolation or loneliness right now have…*" (1 = decreased greatly, 2 = decreased somewhat, 3= stayed about the same, 4= increased somewhat, 5 = increased greatly). Change in food insecurity was measured by asking "*Have your worries about having enough food and being able to pay for food changed since the coronavirus outbreak? Would you say you are…* (1 = no more worried than before the outbreak, 2 = somewhat more worried, 3 = much more worried). Change in financial worries was measured by asking

"Compared to how you felt prior to the COVID-19 pandemic, how much do you worry about your financial situation?" (1 = no change, 2 = worry a little more, 3= worry a lot more).

Statistical Analysis

To address research question 1, bivariate tests (t-tests, χ^2 tests) were used to compare current family caregivers with non-caregivers on all outcome variables. Then, multivariate regression models were estimated with the outcome variables as dependent variables and current caregiving status (yes vs. no) as the key predictor, controlling for sex, age, race, education, household size, household income, marital status, and employment situation. To address research question 2, bivariate tests (t-test, ANOVA, χ^2 test) were used for comparing the CCRI scores across key individual caregiving context variables. Then multivariate regression models were estimated with the outcome variables as dependent variables and the CCRI as the key predictor, controlling for sex, age, race, education, household size, household income, marital status, and employment situation. The caregiver risk models also included the key caregiving context variables as predictors. All models used Ordinary Least Squares Regression (OLS), except for changes in food insecurity and financial worries (three ordinal categories), for which Ordinal regression was used. Statistical tests are evaluated at the α = .05 level, but given the relatively large sample sizes, effect size measures are also presented for key findings.

RESULTS

Sample Socio-Demographic Characteristics

Socio-demographic characteristics are presented separately for family caregivers (n = 576) and non-caregivers (n = 2,933) in Table 1. Family caregivers were predominantly female (76%) with a mean age of 59 years; 87% non-Hispanic white; and more than 60% had at least a

bachelor's degree. The majority of caregivers live in multiple person households; 33% had household incomes below $50,000; and nearly 70% were married. Slightly less than 50% of family caregivers were working for pay, and nearly one-fourth (half of those employed) were working at home due to the COVID pandemic. The non-caregiver comparison sample was similar in terms of socio-demographic profile. Non-caregivers were significantly less likely to be female (68%); more likely to live alone (29%); less likely to be married (57%); and slightly more likely to be working at home due the pandemic (28%). Among both caregivers and non-caregivers, approximately 8% reported losing a job due to the pandemic, and very few in either group reported having to quit a job to take care of family.

Family Caregiver Context

Contextual caregiving variables are presented in Table 2 (n = 576). Slightly more than half (55%) of care recipients were female; and the majority (64%) were over 65 years old, with 38% 80 years or older. More than half of the care recipients lived with the caregiver; the primary condition was a long-term physical condition for almost one half of care recipients, a cognitive / memory problem for about one quarter (including 13% with Alzheimer's Disease / Dementia), and a behavioral, emotional, or developmental disorder for the remaining quarter. Over one-third of the caregivers were the adult child of the care recipient, 25% were spouses, and another 20% were the parent of the care recipient. In terms of broad type(s) of help provided, 42% provided help only with higher level household tasks (e.g., shopping, managing personal finances, arranging for outside services, or providing transportation); 7% provided help with both household tasks and personal care (e.g., bathing, dressing, grooming, eating, toileting, mobility); and 19% helped with both household tasks and medical / nursing tasks (e.g., managing

medications, changing dressing on wounds, or monitoring equipment like oxygen tanks). Nearly 30% of surveyed family caregivers provided help with all three types of tasks.

COVID Caregiver Risk Index (CCRI)

The most commonly reported COVID-related impacts reported on the CCRI included increased caregiving duties (63%), making care provision more emotionally difficult (56%), declines in care recipient mental health (43%), more difficulties getting needed food and medical supplies (41%), and interference with medical treatments like doctor's appointments for the care recipient (37%). The mean number of impacts endorsed was 3.7 out of a possible 12 (median = 3.0).

Research Question 1: Family Caregiver Versus Non-Caregiver Outcomes

Descriptive statistics and comparisons between caregivers and non-caregivers on well-being outcomes are shown in Table 3. Across all five *PROMIS-29* short form measures, family caregivers scored significantly ($p < .01$) worse than non-caregivers – they reported more anxiety, depression, fatigue and sleep disturbance, and less ability to participate in social activities. Also, note that the largest effects for both groups were for the anxiety measure, with family caregivers scoring more than half a standard deviation above national norms. In addition, family caregivers reported significantly ($p < .01$) worse financial well-being than non-caregivers on the adapted *COST* measure. In multivariate models controlling for sex, age, race, education, household size, household income, marital status, and employment situation (included as Supplemental Table 1), *all six of the differences between family caregivers and non-caregivers on concurrent well-being outcomes remained statistically significant* ($p < .01$). Thus, more

negative concurrent outcomes for family caregivers relative to non-caregivers were not due to pre-existing differences in socio-demographic factors included in the models.

Turning to perceived changes since COVID, family caregivers were more likely ($p < .01$) to be much more worried about being able to afford food since the COVID outbreak (7.3%; 21.9% somewhat more worried) than non-caregivers (2.9%; 17.5% somewhat more worried). Family caregivers were also more likely ($p < .01$) to worry a lot more about their financial situation in general since COVID (22.4%; 53.0% worry a little more) than non-caregivers (16.9%; 53.1% worry a little more). In multivariate models controlling for sex, age, race, education, household size, household income, marital status, and employment situation (included as Supplemental Table 2), *these differences between family caregivers and non-caregivers on perceived changes in two of the three well-being outcomes remained statistically significant*. Caregivers did not differ from non-caregivers on perceived changes in loneliness since the COVID outbreak. It should be noted that while these caregiver status differences were statistically significant, all of the effect sizes (Cohens D = .13 - .27; variance explained = 1%) were relatively small.

Research Question 2: Family Caregiver Risk Factors for Negative Outcomes

To begin to understand caregivers most at risk for negative outcomes, we conducted preliminary bivariate analyses of several key family caregiver contextual variables' relationships with the COVID Caregiver Risk Index (CCRI), which are shown in Supplemental Table 3. Parent caregivers ($p < .05$), those providing care for care recipients with cognitive / memory ($p < .01$) and emotional / behavioral / developmental issues ($p < .01$), those providing both personal care and medical / nursing tasks ($p < .01$), females ($p < .05$), and caregivers with lower incomes ($p < .01$) reported the greatest number of effects on the COVID impact index.

To better understand significant family caregiver risk factors for negative COVID-related outcomes, multivariate regression models were estimated with the nine well-being outcomes as dependent variables, and the CCRI and additional risk factors as predictors. All predictors were entered simultaneously. Note that these analyses test the impact of all caregiver risk factors independent of the specific COVID impacts measured via the CCRI. Results for the models for the concurrent well-being outcomes are shown in Table 4. First, across all outcomes, *family caregivers who scored higher on the COVID Caregiver Risk Index (CCRI) were more likely to report negative outcomes (all p < .01), controlling for all other variables.* These were small to medium effects in terms of variance explained (3- 6%). In terms of other risk factors, caregivers of care recipients with cognitive / memory problems, caregivers of care recipients with emotional / behavioral / developmental issues, providing both personal and medical care, female caregivers, younger caregivers, caregivers of younger care recipients, and lower income caregivers were at higher risk for poor outcomes on two or more measures in multivariate analyses.

Multiple regression analysis results for the perceived change outcomes are reported in Table 5. As with the concurrent outcomes, *family caregivers who scored higher on the CCRI were more likely to report increased negative outcomes across all indicators (all p < .01), controlling for all other variables,* with small effects in terms of variance explained (~3%). Caregivers caring for someone with behavioral / emotional / developmental disorders were more likely to report increased financial worries since COVID (p < .05). Caregivers providing personal care help reported increased financial worries since COVID (p < .05). Younger caregivers, caregivers of care recipients under the age of 65, and caregivers with less education and lower income, were more likely to report increased worries about paying for food since the

COVID outbreak (p < .01). Low income caregivers were also more likely to report increased loneliness (p < .05) and general financial worries since COVID (p < .05).

DISCUSSION AND IMPLICATIONS

Our first goal in this study was to compare caregivers and non-caregivers on important social, physical, emotional, and financial outcomes as well as perceived changes due to the pandemic. Scores were significantly worse among caregivers for all five PROMIS-29 outcome measures - anxiety, depression, fatigue, sleep disturbance, and social participation. Caregivers also reported poorer financial well-being than non-caregivers. Caregivers were also more likely to report increased financial and food security worries since the COVID-19 outbreak than non-caregivers. The heightened adverse effects of COVID-19 on caregivers persisted even after controlling for sociodemographic differences between caregivers and non-caregivers, showing that caregivers are additionally vulnerable to the effects of the pandemic.

A second goal of this study was to identify risk factors that predict adverse outcomes among caregivers. This is important because such data provide valuable guidance on whom to target for support and the type of support needed. First and foremost, for all outcomes examined, the COVID Caregiver Risk Index (CCRI) was a significant predictor of adverse effects. The CCRI is comprised of 12 items assessing COVID-19 related stressors in the caregiving experience. We conceptualize this as a summary measure of the primary and secondary stressors and stress appraisals potentially affected by the pandemic. When asked how COVID-19 had changed the caregiving experience, caregivers reported that it increased the effort involved in providing care, made it more physically, emotionally, and financially difficult, made it harder to get prescription medications, interfered with doctor appointments or treatment for the care recipient, and made it more difficult to obtain healthcare. Thus, caregivers who report increased

challenges in performing a wide range of caregiving tasks are particularly vulnerable to adverse effects. Family caregivers for whom COVID-19 had the greatest impacts on primary and secondary stressors and stress appraisals reported the most adverse effects on health and well-being across multiple domains, which is consistent with the stress-health process models described earlier (Pearlin et al., 1990; Schulz & Martire, 2004). In sum, our results suggest that the COVID-19 pandemic involves a variety of factors that may directly impact: (1) *primary stressors* through worsening care recipient physical and mental health, increased caregiving demands, and reduced ability to access formal healthcare for the care recipient; (2) *secondary stressors* like increased financial difficulties and family conflict; and (3) *stress appraisals* of increased physical, emotional, and financial difficulties of providing care. These negative impacts on stressors and appraisals may translate into adverse effects on physical, emotional, social, and economic caregiver well-being (Pearlin et al., 1990; Schulz & Martire, 2004).

Caregiving context variables also played a significant role in identifying caregivers at risk for adverse outcomes, and these findings are independent of or in addition to the impacts on primary and secondary stressors and stress appraisals just described. Across multiple outcomes, caregivers who were female, younger, had lower incomes, were providing both personal and medical care, and provided care to care recipients with cognitive or memory problems or provided care to care recipients with behavioral, emotional, or developmental disorders exhibited more adverse effects. These findings are generally consistent with other risk factor models of caregiving (Schulz & Eden, 2016), but also point to unique subpopulations of caregivers susceptible to adverse pandemic related effects, namely, younger caregivers caring for younger care recipients with behavioral, emotional, or developmental disorders. The findings for age and income are also consistent with population-based national surveys of risk factors for adverse

impacts of COVID-19 in the general population (Ettman et al., 2020; McGinty, Presskreischer, Anderson et al., 2020; McGinty, Presskreischer, Han et al., 2020).

The overriding message conveyed by these data is that the typical challenges of caregiving are exacerbated by the pandemic and associated constraints, such as restricted access to healthcare supports and providers, closure of childcare supports and schools, job loss or reduced work hours, increased concerns about self-care and worsening health of the care recipient, and social isolation due to limits on family visits and work at home requirements. The combined effect of these pandemic-related stressors has increased caregiver burden and demands and reduced well-being across multiple domains.

Addressing these challenges requires a multifaceted approach that includes easing of policies that restrict access to care, enhancing income security through extended unemployment benefits and supportive workplace policies, increased access to and use of technology to ease social isolation, and facilitating access to telehealth support services that have the potential of maintaining the physical and emotional health of both the caregiver and care recipient.

Our findings may also have implications for other public health crises, including future pandemics, natural disasters, and more geographically circumscribed events. Inasmuch as older adults with existing illness and disability are a vulnerable population, any public health crisis is likely to place them at increased risk of adverse effects. The challenges of a public health crisis will inevitably spill over to family caregivers who feel responsible for mitigating the impact of the crisis on their care recipients, while at the same time dealing with their own vulnerabilities. While caregiver sub-groups most at risk for other public health crises may differ somewhat from those reported here, our findings provide initial guidance on potentially vulnerable populations.

In addition, the general policy recommendations just described would address challenges resulting from any public health crisis.

This study has limitations that should be acknowledged. First, this was a nonprobability survey. However, given the urgency of the COVID-19 pandemic and potential impacts on family caregivers, we feel comfortable presenting this information with this caveat in mind. The relatively large and socio-demographically diverse sample size also lends credibility to the generalizability of our findings. Second, although the overall caregiver sample size (n = 576) is sufficient for addressing the research questions, it does not allow for detailed analyses of key sub-groups involving combinations of factors (e.g., younger, female caregivers providing care to a child with emotional / behavioral / developmental issues). Third, the cross-sectional design limits our ability to make clear causal statements about the impacts of the COVID pandemic. It would have been more ideal to have conducted a longitudinal study of caregivers and non-caregivers, including well-being data collected prior to the pandemic onset. However, the normed PROMIS-29 T-scores and the perceived changes due to COVID provide some evidence of impacts of the pandemic, and statistical control of pre-existing socio-demographic variables strengthens the findings. Last, although results were interesting, the CCRI is a newly derived measure and will require further validation in additional samples.

Conclusions

This study highlights the negative effects of the COVID-19 pandemic on family caregivers. Under ordinary circumstances, caregiving is an intense, complex, and potentially stressful undertaking. Our work shows that the pandemic has made an already challenging situation even more so. Family caregivers in this study reported consistently more negative impacts of COVID-19 compared to those not providing care. Using the newly developed *COVID*

Caregiver Risk Index (CCRI), we also found increases in caregiving duties and responsibilities, and that the pandemic has added to the perceived burdens and difficulties associated with care provision. Results were generally consistent with adaptations of classic stress-health process models to family caregivers (Pearlin et al., 1990; Schulz & Martire, 2004). Certain subgroups of family caregivers were at higher risk for negative impacts, including females, those at low incomes, those providing both personal and medical care, and those providing care to care recipients with cognitive or memory problems. While these findings mirror the broader caregiving risk literature (Schulz et al., 2020; Schulz & Eden, 2016), we also found that younger caregivers, those caring for younger recipients, and those providing care for emotional / behavioral problems were also at increased risk. These findings are novel, and combined with the other effects reported here, suggest appropriate targets for interventions and policy discussions. While it might be assumed that COVID-19 would make caregiving even more difficult, this study provides empirical evidence that this is, in fact, the case. Family caregivers should receive increased support and assistance during this serious public health crisis.

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Table 1. Demographics by caregiver status

	CG status		
	Not a CG	CG	
Demographic	(N=2,933)	(N=576)	*P*
Sex			
% Male	31.8	24.5	<.001
% Female	68.2	75.5	
Age			
Minimum, maximum	18, 100	18, 91	.43
Median	63	61	
Mean	58.4	59.0	
Standard deviation	16.7	13.9	
Interquartile range	23	18	
Race			
% Non-Hispanic White	89.7	86.7	.09
% Non-Hispanic Black	5.8	6.5	
% Non-Hispanic other race or multiple races	3.0	4.6	
% Hispanic	1.5	2.3	
Education			
% High school or less	7.6	9.4	.12
% Some college	24.2	26.8	
% Bachelor's degree	30.5	30.6	
% Master's degree or higher	37.7	33.2	
Household Size			
% 1	28.9	10.6	<.001
% 2	44.0	47.6	
% 3 or more	27.1	41.8	
Household Income			
% < $25,000	9.5	11.6	.43
% $25,000 - $49,999	20.2	21.4	
% $50,000 - $99,999	38.4	36.8	
% $100,000 and higher	28.5	26.4	

% Missing	3.4	3.8	
Marital Status			
% Married	57.1	68.6	<.001
% Divorced	13.3	11.3	
% Widowed	9.7	4.0	
% Single	19.9	16.1	
Employment Situation			
% Not working for pay	53.7	52.6	.009
% On site	13.3	13.7	
% At home (normal location)	5.5	9.0	
% At home (due to pandemic)	27.5	24.7	
Lost Employment Due to COVID-19	7.7	8.2	.73

Notes. Caregiver=CG; COVID-19=Coronavirus disease 2019.

Table 2. Caregiving characteristics (n = 576)

Caregiving characteristic	%
CR Sex	
Male	45.3
Female	54.7
CR Age	
0-44	22.5
45-64	13.8
65-79	26.2
80 or older	37.5
CR Residence	
In CG household	56.4
Outside of CG household	43.6
CR Primary Condition	
Cognitive / memory problem	25.4
Behavioral, emotional, or developmental disorder	25.4
Physical condition	49.3
CR Diagnosed with Alzheimer's Disease / Dementia	
Yes	13.4
No	86.6
CG Relationship to CR	
CG is spouse of CR	25.2
CG is adult child of CR	34.5
CG is parent of CR	19.8
CG is friend / other relative of CR	20.5
Type of Care Provided by CG to CR	
Household tasks (only)	42.0
Personal care tasks (only)	1.1
Medical / nursing tasks (only)	0.7
Household & personal care tasks	7.2
Household & medical / nursing tasks	19.0
Personal care & medical / nursing tasks	0.4

All three types of care	29.5
COVID Impacts on Caregiving	
1. Required change in who is providing care	23.1
2. Increased CG's efforts or duties	62.8
3. Made providing care more physically difficult	22.2
4. Made providing care more emotionally difficult	55.9
5. Made providing care more financially difficult	20.3
6. Made it harder to get basics like food & medical supplies	41.3
7. Made it harder to get prescription medications for CR	12.2
8. Interfered with doctor appointments or treatment for CR	36.8
9. Interfered with CG's healthcare	21.4
10. Led to family disagreements or conflict over caring for CR	16.5
11. Led to declines in CR's physical health	9.9
12. Led to increased worry, fear, depression, sleep problems, or other declines in CR's mental health	43.2
COVID Caregiver Risk Index (CCRI; count; range = 0-12)	Mean = 3.66 Mdn = 3.00

Notes. CR=care recipient; CG=caregiver.

Table 3. Outcomes by caregiver status

Outcome	Not a CG (N=2,933)	CG (N=576)	*P*
Anxiety			
Mean	54.6	56.6	<.001
SD	9.2	9.3	
Depression			
Mean	51.1	52.2	.004
SD	8.8	9.2	
Fatigue			
Mean	49.4	52.3	<.001
SD	10.5	10.8	
Sleep Disturbance			
Mean	50.6	52.2	<.001
SD	8.4	8.8	
Able to Participate			
Mean	47.3	46.1	.004
SD	9.5	9.3	
Financial Well-being			
Mean	27.9	25.7	<.001
SD	9.3	9.6	
Loneliness			
% Increased	61.4	62.1	.15
Food Worries			
% Much more worried	2.9	7.3	<.001
Financial Worries			
% Worry a lot more	16.9	22.4	.001

Notes. CG=caregiver.

Table 4. Caregiver risk models for mental health, physical symptoms, social participation, and financial well-being during COVID-19

Predictor variable	Anxiety (n = 545)			Depression (n = 548)			Fatigue (n = 548)			Sleep Disturbance (n = 548)			Social Participation (n = 544)			Financial Well-Being (n = 547)		
	B	SE	*P*	B	SE	*P*	B	SE	*P*	B	SE	*P*	B	SE	*P*	B	SE	*P*
COVID Caregiver Risk Index (CCRI)	0.35	0.06	<.001	0.25	0.06	<.001	0.44	0.07	<.001	0.26	0.07	<.001	-0.32	0.08	<.001	-0.82	0.15	<.001
Relationship to CR (ref: Adult child of CR)																		
CG is spouse of CR	0.18	0.54	.74	-0.29	0.54	.59	0.89	0.63	.16	0.81	0.61	.18	-0.48	0.69	.48	-0.14	1.36	.92
CG is parent of CR	0.56	0.77	.46	-1.05	0.78	.18	0.42	0.90	.64	0.16	0.87	.85	-0.15	0.98	.88	-0.25	1.95	.90
CG is friend/other relative of CR	-0.05	0.44	.92	-0.46	0.45	.31	-0.02	0.52	.97	0.38	0.50	.45	0.19	0.57	.73	0.72	1.12	.52
CR Condition (ref: Physical condition)																		
Cognitive/memory problem	0.16	0.38	.68	1.02	0.39	.01	0.73	0.45	.10	0.37	0.44	.39	-1.06	0.49	.03	0.00	0.98	>.99
Behavioral/emotional/developmental disorder	1.13	0.45	.01	1.25	0.45	.01	1.53	0.52	<.001	0.53	0.51	.30	-0.61	0.57	.29	-0.90	1.14	.43
CR Residence (ref: Outside of CG household)																		
In CG household	0.09	0.39	.82	0.35	0.39	.38	0.25	0.46	.58	-0.07	0.44	.88	-0.49	0.50	.32	0.26	0.99	.80
Type of Help Provided (ref: Household tasks)																		
Personal care only	0.15	0.60	.80	-0.32	0.61	.61	-0.06	0.71	.93	0.20	0.69	.77	0.74	0.77	.34	-2.77	1.53	.07
Medical/nursing tasks only	0.23	0.41	.58	0.41	0.42	.33	0.80	0.49	.10	0.13	0.47	.78	-0.03	0.53	.96	-0.62	1.05	.56

Predictor variable	Anxiety (n = 545)			Depression (n = 548)			Fatigue (n = 548)			Sleep Disturbance (n = 548)			Social Participation (n = 544)			Financial Well-Being (n = 547)		
	B	SE	P	B	SE	P	B	SE	P	B	SE	P	B	SE	P	B	SE	P
Both personal care and medical tasks	-0.47	0.39	.22	-1.00	0.39	.01	0.08	0.45	.86	0.00	0.44	.99	1.02	0.49	.04	-0.10	0.98	.92
CG Sex (ref: Male)																		
Female	0.72	0.35	.04	0.19	0.36	.60	0.85	0.41	.04	-0.23	0.40	.56	-1.11	0.45	.01	-0.74	0.89	.41
CG Age	-0.07	0.01	<.001	-0.07	0.01	<.001	-0.07	0.02	<.001	-0.06	0.02	<.001	0.01	0.02	.52	0.18	0.04	<.001
CR Age (ref: 80 or older)																		
0-44	0.02	0.79	.98	1.65	0.80	.04	0.15	0.92	.87	0.05	0.90	.96	-0.58	1.01	.57	-0.11	2.00	.95
45-64	0.33	0.57	.57	1.01	0.58	.08	1.37	0.67	.04	0.80	0.65	.22	-0.37	0.73	.61	-0.01	1.45	.99
65-79	0.76	0.43	.07	1.06	0.43	.01	0.24	0.50	.63	-0.15	0.48	.76	-0.08	0.55	.88	-0.10	1.08	.92
CG Race (ref: Non-Hispanic White)																		
Non-Hispanic Black	-0.99	0.61	.10	-1.33	0.62	.03	0.15	0.72	.84	-1.16	0.70	.10	1.09	0.78	.16	1.90	1.55	.22
Non-Hispanic other race or multiple races	-0.78	0.73	.29	-0.64	0.73	.38	-0.44	0.84	.60	0.85	0.82	.30	1.19	0.91	.19	0.99	1.82	.59
Hispanic	-0.46	0.98	.64	-1.17	1.00	.24	-1.94	1.15	.09	1.30	1.12	.25	0.26	1.25	.83	-2.71	2.50	.28
CG Education (ref: HS or less)																		
Some college	-0.35	0.57	.53	-0.59	0.58	.31	0.49	0.67	.47	-0.06	0.65	.92	-0.21	0.73	.77	0.06	1.45	.97
Bachelor's degree	-0.96	0.58	.10	-1.33	0.58	.02	0.52	0.67	.44	-0.33	0.66	.61	-1.28	0.73	.08	0.59	1.46	.69

Predictor variable	Anxiety (n = 545)			Depression (n = 548)			Fatigue (n = 548)			Sleep Disturbance (n = 548)			Social Participation (n = 544)			Financial Well-Being (n = 547)		
	B	SE	P	B	SE	P	B	SE	P	B	SE	P	B	SE	P	B	SE	P
Master's degree or higher	-0.52	0.59	.38	-1.03	0.60	.09	0.65	0.69	.35	-0.48	0.68	.48	-1.01	0.76	.18	1.52	1.50	.31
CG Income (ref: <$25,000)																		
$25,000 - $49,999	-0.50	0.50	.32	-1.15	0.50	.02	-0.35	0.58	.55	0.43	0.57	.45	0.73	0.64	.25	0.60	1.26	.63
$50,000 - $99,999	-1.01	0.48	.04	-1.68	0.48	<.001	-1.33	0.56	.02	-0.68	0.55	.21	1.00	0.61	.10	3.77	1.21	<.001
$100,000 and higher	-1.40	0.53	.01	-1.88	0.53	<.001	-2.29	0.62	<.001	-0.54	0.60	.37	1.48	0.68	.03	7.05	1.34	<.001
Employment Situation (ref: Not working for pay)																		
On site	0.00	0.47	.99	-0.25	0.48	.60	0.67	0.55	.23	0.18	0.54	.74	0.22	0.60	.71	-1.13	1.19	.34
At home (normal location)	-0.12	0.55	.83	-0.05	0.55	.93	0.41	0.64	.52	-0.58	0.62	.35	-0.32	0.69	.65	1.17	1.38	.40
At home (due to pandemic)	0.71	0.42	.09	0.41	0.42	.33	1.11	0.49	.02	0.40	0.47	.40	-0.56	0.53	.29	0.17	1.05	.87

Notes. COVID-19=Coronavirus disease 2019; CR=care recipient; CG=caregiver; HS=high school.

B= non-standardized regression coefficient.

Anxiety, depression, fatigue, sleep disturbance, and social participation are from the Patient-Reported Outcomes Measurement Information System (PROMIS)-29 measure.

Financial well-being is an adapted version of the FACIT Comprehensive Score for Financial Toxicity (COST) – higher scores mean higher financial well-being.

Table 5. Caregiver risk models for perceived change in loneliness, food insecurity, and financial worries due to COVID-19

Predictor variable	Worsened Loneliness[a] (N = 548)			Increased Food Worries[b] (N = 548)			Increased Financial Worries[b] (N = 549)		
	B	SE	*P*	Estimate	SE	*P*	Estimate	SE	*P*
COVID Caregiver Risk Index (CCRI)	0.04	0.01	<.001	0.16	0.04	<.001	0.15	0.04	<.001
Relationship to CR (ref: Adult child of CR)									
CG is spouse of CR	-0.07	0.13	.61	0.36	0.39	.36	-0.23	0.31	.45
CG is parent of CR	-0.07	0.19	.71	-0.02	0.52	.96	0.38	0.44	.39
CG is friend / other relative of CR	-0.08	0.11	.49	0.06	0.31	.85	-0.28	0.25	.28
CR Condition (ref: Physical condition)									
Cognitive / memory problem	0.08	0.09	.37	0.44	0.28	.12	-0.02	0.22	.94
Behavioral/emotional/developmental disorder	0.16	0.11	.15	0.14	0.32	.66	0.68	0.26	.01
CR Residence (ref: Outside of CG household)									
In CG household	0.16	0.10	.08	-0.52	0.28	.06	-0.24	0.22	.29
Type of Help Provided (ref: Household tasks)									
Personal care only	-0.11	0.15	.44	0.73	0.40	.07	0.75	0.35	.03
Medical/nursing tasks only	-0.05	0.10	.60	-0.19	0.31	.53	0.05	0.24	.83
Both personal care and medical tasks	-0.14	0.09	.15	-0.08	0.28	.78	0.02	0.22	.94
CG Sex (ref: Male)									

Predictor variable	Worsened Loneliness[a] (N = 548)			Increased Food Worries[b] (N = 548)			Increased Financial Worries[b] (N = 549)		
	B	SE	*P*	Estimate	SE	*P*	Estimate	SE	*P*
Female	0.06	0.09	.50	-0.38	0.26	.14	0.37	0.20	.07
CG Age	-0.01	0.00	.09	-0.04	0.01	<.001	-0.01	0.01	.36
CR Age (ref: 80 or older)									
0-44	-0.14	0.19	.46	1.09	0.53	.04	-0.45	0.46	.32
45-64	-0.08	0.14	.56	0.85	0.39	.03	-0.41	0.33	.21
65-79	0.07	0.10	.52	0.19	0.32	.55	-0.01	0.25	.96
CG Race (ref: Non-Hispanic White)									
Non-Hispanic Black	-0.17	0.15	.26	0.48	0.38	.21	-0.60	0.35	.09
Non-Hispanic other race	-0.12	0.18	.52	0.05	0.46	.92	-0.24	0.42	.57
Hispanic	-0.31	0.24	.20	0.57	0.60	.35	1.13	0.59	.06
CG Education (ref: High school or less)									
Some college	0.14	0.14	.31	-0.13	0.36	.71	-0.13	0.33	.69
Bachelor's degree	0.16	0.14	.25	-0.96	0.38	.01	-0.14	0.33	.67
Master's degree or higher	0.15	0.15	.30	-0.84	0.39	.03	-0.15	0.34	.66
CG Income (ref: <$25,000)									
$25,000 - $49,999	-0.21	0.12	.09	-0.13	0.30	.66	-0.03	0.29	.91
$50,000 - $99,999	-0.25	0.12	.04	-0.97	0.31	<.001	-0.70	0.28	.01
$100,000 and higher	-0.29	0.13	.02	-2.12	0.41	<.001	-0.68	0.31	.03
Employment Situation (ref: Not working for pay)									

Predictor variable	Worsened Loneliness[a] (N = 548)			Increased Food Worries[b] (N = 548)			Increased Financial Worries[b] (N = 549)		
	B	SE	*P*	Estimate	SE	*P*	Estimate	SE	*P*
On site	-0.06	0.12	.61	-0.42	0.33	.21	0.36	0.27	.18
At home (normal location)	-0.16	0.13	.22	-0.05	0.42	.91	0.09	0.31	.77
At home (due to pandemic)	-0.08	0.10	.43	-0.03	0.31	.92	0.20	0.24	.41

Notes. COVID-19=Coronavirus disease 2019; CG=caregiver; CR=care recipient.

B=non-standardized regression coefficient.

[a] Ordinary least Squares (OLS) regression.

[b] Ordinal regression.